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**A Qualitative Study to Assess the Impact of
Iatrogenic Trigeminal Nerve Injury**

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Abstract

AIMS: This is a qualitative study to deepen knowledge of the impact of iatrogenic trigeminal nerve injury on dental patients.

METHODS: One to one semi-structured interviews and workshops were conducted with 12 patients who had incurred a nerve injury from dental treatment. Nerve injury was diagnosed by oral surgeons via a series of neurosensory tests. Interpretative phenomenological analysis was used to analyse the narratives from the interviews.

RESULTS: Key themes are presented and discussed. These include the personal impact for the patient, which includes a change in self-perception, the impact on relationships, the impact on oral healthcare and adjustment to the injury over time. Patients also discussed a change in how they perceived their dentist and other healthcare professionals, and highlighted factors they would like to change within the dental care system.

CONCLUSION: Recommendations are made for clinical practice and future research.

Introduction

Iatrogenic trigeminal nerve injury is the most problematic consequence of dental surgical procedures. Injury of the trigeminal nerve is a recognised complication of several dental procedures, including removal of the lower 8s, implants, endodontics and local anaesthetic injury¹. It is estimated that between 1% and 20% of lower 8 removals result in some form of trigeminal injury, most of which are temporary. However about 0.5-2% of nerve injuries lead to ongoing symptoms, which include neuropathic pain, altered sensation and numbness in the majority of patients².

The incidence of lingual nerve injury rates is increasing, particularly in the USA, possibly to the increased rate of implant surgery and endodontic therapy³. The majority of lingual nerve injuries resolve when related to lingual access third molar surgery which is now rarely undertaken, however, inferior alveolar nerve injuries are predominantly temporary when related to local anaesthesia, but permanent when related to implant, endodontic and third molar surgery. The consequences of injury are complex, and present patients with a variety of functional and psychological issues. Approximately 34%-70% of nerve injuries lead to neuropathic pain, whilst other troublesome symptoms include intra and extra-oral numbness, loss of taste function, dribbling, difficulties with articulation and mastication, kissing, shaving or applying makeup and sleeping.⁴ Nerve injury patients report impairment in work roles, socialising and family roles and have a more negative view of themselves and dental professionals⁴. The emotional and psychological impact of such injuries is often great and some patients referred for specialist assessment require additional support to improve their mental health and return to a good quality of life.⁵

Current management of iatrogenic trigeminal injuries is generally conservative, although occasionally surgical repair may be indicated. At present, conservative management mainly consists of explanation, reassurance, analgesics and prevention of secondary dental problems (e.g. by encouraging dental hygiene despite pain).⁶

Surgery is not effective for trigeminal neuropathic pain,⁷ thus the emphasis of care is predicated on medical and psychological intervention.⁶ Specialist assessment of these patients reveals marked levels of anxiety, post-traumatic symptoms and phobic avoidance of dentists⁶. Oral health-related quality of life (OHRQoL) becomes an important issue in the assessment and treatment of patients that suffer from chronic facial pain⁸. The general literature on chronic pain also shows that chronic pain has a significant personal impact on patients, and has a detrimental impact on their social life, family relationships and health care services.^{9,10} Further information is needed on how trigeminal nerve injury patients perceive their injury and the impact on their life.

Qualitative research exploring narrative representations of health and illness offers a counter-balance to the dominant biomedical focus. Philosophers have suggested that we create frames for understanding and judgement, and link them to everyday circumstances in our lives by drawing on diverse moral and political discourses. The narrative is a central way in which we perceive experience and judge our actions and the course and value of our lives.¹¹ There are three different kinds of illness

narratives; illness *as* narrative, narrative *about* illness, and narrative *as* illness¹¹.

Increasingly the way in which people talk about and present events is seen as critical, and reflects something of the self-image that the narrator hopes to convey to others. It has been suggested that chronic illness or injury can be thought of as a disruption of the person's identity and surrounding world¹². Attention is paid to bodily processes not normally paid attention to, and decisions about seeking help. Pain becomes a form of bodily alienation or betrayal¹³

It has been suggested that a chronic illness or injury changes the focus of attention, and people can become focused on help seeking. A chronic condition impacts at a core level on identity⁹. When pain is a factor of illness or injury, people can feel betrayed by their body. This in turn raises its salience and threat, and is a key factor in hypervigilance.¹⁰

This study aimed to explore the impact of iatrogenic trigeminal nerve injury on dental patients, with a view to developing targeted psychological support. We used qualitative methods to do this in order to gain a more complete understanding of patients' experience of sustaining these injuries and to ensure that important areas were not overlooked. The results of the study will be compared to the results of similar work that has been undertaken with facial pain patients and the similarities and differences used to inform our ongoing efforts to develop effective management strategies for patients with iatrogenic nerve injury.

Method

Ethics approval for the study was obtained from the NRES Committee South West - Central Bristol (Study Number: 12/SW/0349). We drew on approaches within qualitative research of interpretative work which aims to 'see through the eyes of' and, to a lesser extent, of 'grounded theory' to identify and refine key themes from interviews through a process of iteration and saturation^{14,15}. These themes were then shared in a patient workshop to provide a point of triangulation with a different set of iatrogenic injury patients. This was a workshop run for the clinical benefit of patients who had incurred a nerve injury, and was run by an oral surgeon, a psychologist and a psychiatrist. This was developed further by comparison with clinic and interview narratives of patients who had sustained non-iatrogenic trigeminal injuries. The one non-iatrogenic interview and five cases reviewed did not share the same traumatised illness narrative found in the iatrogenic cases. Although a relatively small sample, no negative cases (i.e. iatrogenic injury with a narrative more similar to non-iatrogenic cases) were discovered. Sharing the iatrogenic injury narratives in the workshop also suggested future opportunity for comparative action research¹⁶ to inform subsequent clinical work in individual sessions and group workshops.

A pragmatic approach was adopted for selection of research subjects, with opportunistic sampling via the clinics within which one of the research team was working as clinical psychologist. One to one interviews were held with 12 patients who had sustained iatrogenic trigeminal nerve injury within the past three years. Patients were recruited from the assessment service for this patient group, which operates from King's Dental Institute in London and receives referrals nationally from

general dental practitioners, oral surgeons and maxillo-facial surgeons. Patients included were those diagnosed with nerve injury of the sensory divisions of the maxillary or mandibular branches of the trigeminal nerve. All patients, prior to recruitment, underwent a trigeminal nerve examination carried out by a qualified oral surgeon, which included neurosensory tests and patient interview⁴, to confirm trigeminal nerve injury.

Interviews were conducted entirely separately from clinic contact, and it was strongly emphasised at initial invitation, seeking of consent, and at interview that care was in no way dependent on participation. As consent is an ongoing process, participants were free to withdraw from involvement at any time during and after contact with the researchers. Interviews were conducted by telephone and tape recorded.

Interviews were conducted by a trained researcher, who followed a semi-structured interview schedule adapted from use with facial pain patients. The interviews lasted for approximately 30 mins and covered a small number of questions (5-10) designed to elicit the participants narrative of the circumstances of their iatrogenic injury and subsequent impact on everyday life, plus more general background about their approach and attitude to both dental and other medical care before and after the injury. This schedule was based on narratives from clinics and a previous clinical workshop run for nerve injury patients. Interviews were digitally recorded and transcribed by an independent transcription service, before being qualitatively analysed. Anonymity was assured, and where quotes were subsequently used for

illustrative purposes in documentation any individual identifying details were removed.

Analysis

An interpretative phenomenological approach was used to analyse the narratives from the interviews, with the emphasis on 'seeing through the eyes' of the participants. Grounded theory was also used to a lesser extent, to identify and refine key themes from interviews through a process of iteration and saturation^{11,12}.

Analysis was ongoing, and as is usual with such qualitative approaches, data collection ceased once saturation of emerging themes was judged to have been achieved within the confines of the small scale nature of the study. Coding involved the development of themes and categories that were relevant to the impact of these injuries on patient experience.¹³ Memo documents which summarised the interviews and identified emergent themes were created by the social science member of the research team and circulated for discussion within the team as each couple of interviews were conducted. This allowed for checking that the original interview schedule was suitable and to assess, refine and agree themes as the study progressed.

Multiple, strong themes emerged from this analysis. To ensure that the account was rich, robust, comprehensive and well-developed, we then presented the themes to another workshop for nerve injury patients and asked for responses. O'Donoghue and Punch¹⁷ note that triangulation is a "method of cross-checking data from multiple sources to search for regularities in the research data" and also suggested opportunity for a form of 'action research'. Action research is an interactive

collaborative inquiry process that aims to bring parties together to enable future personal and organisational change ¹⁸.

Results

Broad themes emerged from the research, which are illustrated in the text below with patients' statements. The diagram below is a summary of these themes.

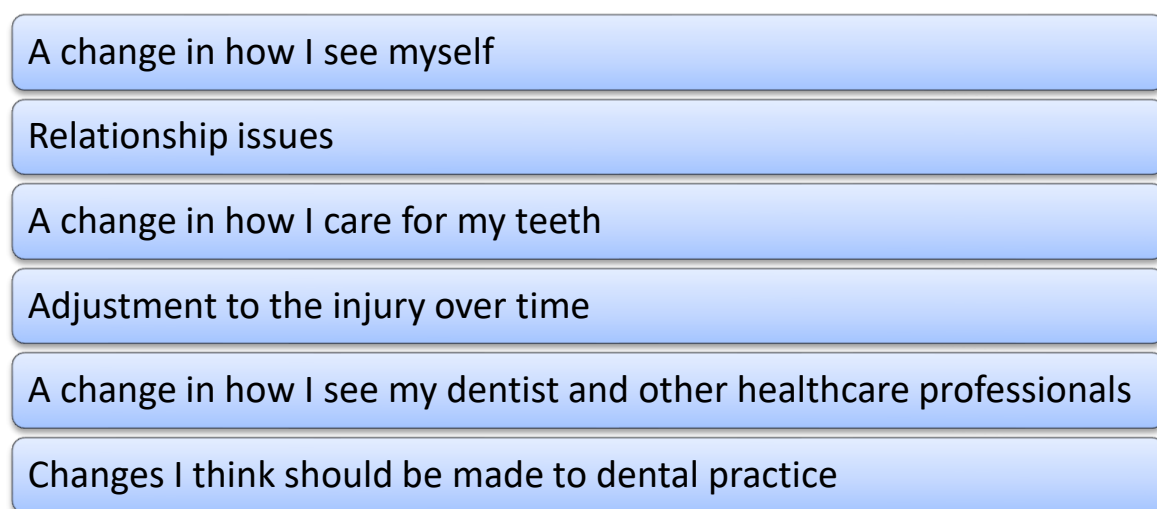


Figure 1: Summary of Key Themes

1. The theme of '**a change in how I see myself**' was striking amongst patients. Respondents varied in how much they said the nerve injury had affected how they saw themselves, but this theme emerged for most people. One patient said, '*I didn't realise at first how much but I think it made me shy and nervous, less confident, a bit snappy and angry*'. People often felt they were more sensitive. Another commented, '*I'm now very paranoid because I can only eat on the left and then I'm paranoid that I've got fillings in every teeth and my teeth hurt*'. This patient said they now felt enclosed and paranoid about their speech.

People talked about the sensation that following the nerve injury their face was now distorted. People described feeling like a 'freak', and said they felt less attractive. Some said that they felt like a victim, others commented that they felt tougher as they had to learn to cope with an injury.

2. The second theme was around '**relationship issues**'. Post nerve injury relationships were universally described as more negative. The nerve injury embodied a sense of betrayal which permeated other relationships, and sometimes led to them ending. Respondents talked about how having a nerve injury had affected how they related to other people. They said they were frequently stressed and irritable, and that they were harsher with other people. One said, *'my sister commented that since I have had the injury I have changed, I am very harsh, you know and I'm more harsh and isolated, a lot less sociable. I don't want to socialise, one because at the beginning although it is not happening now, at the beginning I was feeling uneasy to eat. Another said, 'It's so difficult, where do you go from here? Trying to have your everyday life is so hard. I'm not taking on board what people are saying'*.

People coped in different ways; many tried to hide how they were feeling, but this then affected relationships; *'I hide things quite a lot and when I came here I didn't realise how much I brushed over or hid.. because I was on such a mission to fix it and then when I found out I couldn't ... coming here and obviously the more you learn about it and the more you hear and the more you talk to people and stuff, the more you realise how much you've buried of how it bothered you..'*

Patients said they knew other people were often aware of the injury, but avoided discussing it as they didn't want to upset the patient

3. The third theme was around the '**a change in how I care for my teeth**' This theme varied widely between patients, and could be seen as a continuum. Some patients just avoided brushing/touching the area of injury; *'Sometimes it overwhelms you with the pain and you have to do something else'*. Others reported becoming more 'paranoid' about oral healthcare and spent a lot of time focused on cleaning *'It's like a paranoia; I'm constantly worrying about teeth'*. All patients worried about future extractions.

4. The fourth theme was how respondents had '**adjustment to the injury over time**'. Most patients are angry when the injury first occurs. Patients often initially cope by thinking sensation will return and pain will subside. When they are told the injury is permanent it can shatter this way of coping and lead to depression. This depression gradually moves onto acceptance of the situation, *'I've got to get my head around the fact this is permanent, but I keep saying "what if...?"'. My counsellor is doing bereavement work with me'*. *'Some days it's unbearable, and other days I think I'm doing OK'*.

5. There was a fifth theme around '**a change in how I see my dentist and other health professionals**'. The lengthy wait between the initial identification of problem and an eventual referral to specialist dental services was mentioned by many. *'Our dentist was very dismissive in telling me that there was nothing wrong with me and that I was over reacting and that it will be fine even though he wouldn't put an*

injection in that side, nor would he touch it and then the, the other doctors and stuff telling me...just get on with it.

The initial lack of diagnosis makes it harder for the patient to be legitimately 'sick' and access associated benefits, which some said could sometimes lead to them being seen as a 'difficult' patient. Legal services were often involved, and the patient was forced to advocate and campaign for help across healthcare services. This led to a loss of trust and confidence in dental care, and patients were universally a lot more cautious with dentists and more aware of the business side of dentistry. The lack of trust in dentists typically was extended across healthcare to doctors and nurses, and changed people's decision making on how to obtain help in the future from healthcare services. However patients praised the benefits of specialist dental services; *'Coming here I don't feel like a freak'. I think that was a big turning point to see other people with the injuries, to find out that other people are ... like they were getting more success than me but seeking legal action so I didn't then feel like I was being like bad for doing that...*

The sixth theme was around ***changes nerve injury patients want to dental practice***. Consent issues were frequently mentioned. They stressed that GDPs should explain the procedure and what they are doing more, should be prepared to stop and reassess if a procedure is going wrong, and not just try and continue. They thought that there should be leaflets on trigeminal nerve injury so people are more aware of the issue and specialist treatment; *'I think all dentists should really sit down with patients and explain, sit down and explain that consent form properly. Because it doesn't say you will get a nerve injury, it doesn't so we need to have it documented*

so that you know that they read it for you and you understood it. I remember I sat on that long chair and then he said oh before you put your head up just sign here, so he gave me that paper and I signed’.

Discussion

While limited to a small scale study, our experience was that the identification and subsequent use of the narrative themes in workshops and individual sessions, enabled patients to reflect and identify with others. Chronic pain is known to have a significant impact on quality of life. The narratives provided by respondents provided a rich insight into the impact of trigeminal nerve injury. Presentation of the themes provided a framework to help patients more readily articulate their own feelings and difficulties. This in turn helped them to feel more supported and be more accepting of themselves with an injury, which facilitated processing of the associated grief. A discussion of the identified themes is presented below. These are discussed in relation to current literature.

Change in self-perception

The theme **‘a change in how I see myself’** fits with other literature on chronic pain. Nicole Tang discussed the concept of ‘Mental Defeat’; essentially negative self-evaluation resulting from pain experiences¹⁹. Pain-specific mental defeat may be linked to disability and the seeking of specialist treatment. Elevated levels of mental defeat in chronic pain patients distinguish treatment seeking from non-treatment

seeking individuals²⁰. One patient in the triangulation group discussed how she had a conversation with a friend who was dying from cancer, and both confided that each would like to be in the others' place. To this patient, death seemed preferable to a lifetime of living with chronic facial pain from a nerve injury.

Patients who had incurred an injury to the trigeminal nerve talked about feeling like a freak and a victim. Many felt that their injury was highly apparent to other people, as their face looked distorted and their speech was affected. Many talked about feeling less attractive, and when combined with being unable to kiss without being in pain, the impact on relationships was significant. Some patients felt the experience made them see themselves as stronger, as they had had to fight to get recognition of the injury and its impact. Williamson and Wallace²¹ discussed the impact of iatrogenic adverse changes in appearance, and discussed how medical procedures can impact on body attachments, and our findings added to this body of research on the impact of iatrogenic injuries.

Addressing this change in self-perception through psychological therapies would seem fruitful. Studies with chronic pain patients have demonstrated that working with feelings of mental defeat could prevent severe depression, anxiety and interference with daily life^{19,20}. Nagata et al have demonstrated that mental defeat can be effectively targeted in panic disorder using cognitive-behavioural therapy²². Further studies could apply this to the mental defeat associated with trigeminal nerve injury.

The second theme highlighted, **Relationship issues**

Patients discussed how the nerve injury had impacted on their relationships. This is again not surprising, given that persistent pain is known to have a profound impact on relationships²³. A common theme for patients with trigeminal nerve injury was feeling they treated others more harshly; they were more irritable and felt constantly stressed. For some patients their relationship was so affected it ended. Trust was also affected. The breakdown of trust with their dentist permeated other relationships, and patients said they were hypervigilant to being betrayed again.

Avoidance of talking about the nerve injury was discussed as a strategy used both by the patient, but also by close relatives and friends. Patients often hid their injury, and friends and relatives avoided talking about the injury as they did not want to upset the patient. Herta Flor discussed the impact of chronic pain on spousal relationships²⁴ and noted that not only did chronic pain impact on marital relationships, it also led to heightened distress and physical symptoms in spouses as well. This is something that could be investigated in further research on trigeminal nerve injury.

The third theme '**a change in how I care for my teeth**' reflected issues of avoidance or more commonly, increased focus, again consistent with the chronic pain literature. Models of pain related fear predict hypervigilance and catastrophising²⁵. The process of hypervigilance involves a rapid scan of the situation, which then narrows to a highly focused level of attention if a potential threat is spotted. Hypervigilance is characterised by increased physical and psychological

arousal and is often associated with PTSD. Further research as to whether nerve injury patients fulfil criteria for PTSD is warranted. Patients discussed paying increased attention to their oral healthcare as a way of preventing the need for further dentistry. Psychological support could usefully address this hypervigilance, to enable patients to achieve a positive balance between good oral healthcare and overfocusing. Support to return to mainstream dentistry is also useful for patients following a nerve injury as many had avoided returning to their GDP.

The fourth theme of '**adjustment to the injury over time**' encompassed issues of loss, and the myriad of emotions of shock, denial, anger, depression and trying to make sense of the change. In trigeminal nerve injury the level of disability is often a shock to patients, and they typically move through a cycle of loss as the reality of the permanent change in how their face feels and functions becomes apparent.

Chronic pain is often accompanied by loss, and can lead to feelings that mirror those involved in a grief reaction, involving anger and depression. The grief cycle by Elizabeth Kubler-Ross outlines the emotional stages that many people go through, although it is a rare person who follows the stages in a straightforward way²⁶. More common is for feelings from the different stages to emerge at different salient times. Addressing these feelings in psychological therapy would seem an essential role of the specialist dental service working with trigeminal nerve injury patients. Acceptance and Commitment Therapy, a third wave CBT can provide a framework for addressing this issues in an evidence based way²⁷.

The sixth theme was **‘a change in how I see my dentist and other healthcare professionals’**. There was often a significant loss of trust with healthcare professionals, which impacted on how patients coped. When in 'survival' mode, individuals made themselves 'safe' by looking after their own interests, avoiding or denying threats or difficult issues, or attacking others who they perceived as threats. This can have a significant impact on patients' overall health, as they may avoid visiting dentists and doctors, or end up in conflict laden encounters if they do not get the results they expect from a consultation. It has been suggested that there is also a generic declining trust in healthcare²⁸, and this may compound issues associated with iatrogenic injury. Recognising the impact that iatrogenic injury has on a patient can facilitate understanding and treatment. Staff themselves are often affected by iatrogenic injury, and support for the shame, guilt and depression that can result would further help to smooth potential barriers in the care pathway. Despite an entrenched belief that doctors should be infallible, errors are inevitable, and practitioners often take personal responsibility for errors which can impact on their self-confidence and subsequently on performance²⁹. Penson et al³⁰ discussed how iatrogenic injury can impact on staff practice, sometimes positively, sometimes negatively as staff practice in a more defensive way. In five Harvard emergency departments, it was found that introducing benchmarking as well as quality improvement methods helped to reduce patient related medical errors³¹, and this should be considered to help reduce trigeminal nerve injury.

The seventh theme was **‘changes I think should be made to dental practice’**. Patients stressed the importance of ensuring informed consent at the earliest stages. Patients who had incurred an iatrogenic nerve injury said they wished the risks of

treatment had been more fully explained to them, and they could have weighed the options of alternative treatments or no treatments against intervention. Most risk management professionals recommend using written consent documents for all treatment procedures that are invasive or present a high risk. As the law on informed consent has changed following a Supreme Court judgment (2015) ³², a radical reassessment of current consent practice in dentistry is underway. It is possible that the dental practitioners involved did consent patients, but this was not the recollection of the patients.

Patients said that they wanted it known that the dentist should be prepared to stop and reassess if a procedure is going wrong, not just try and continue. They wanted greater explanation about what was happening during a procedure, and there should be leaflets on trigeminal nerve injury so people are more aware of the issue. Renton and Yilmaz⁶ reviewed management of iatrogenic nerve injury, and conducted a literature review. They advised a holistic approach to management, and provided a summary of key changes in practice that will reduce iatrogenic nerve injuries related to dentistry.

This was a small, qualitative study and several limitations must be noted.

Quantitative research designs the study to address threats to validity through features such as randomization and controls. Norris³³ noted that although the traditional notion of validity is not applicable to qualitative research, a practical way to think about the issue of validity is to focus on error and bias. The method of participant selection may have introduced some bias since all potential participants were attending a NHS clinic. It is possible that

there are people with iatrogenic nerve damage who are living full and rewarding lives, who do not seek support from specialist services, or people who access private health care. It might have been interesting to purposively select for the degree of expressed impact in order to explore factors that aid resilience. This is a potential project for future exploration. There was also the issue that some patients were also being seen by the Clinical Psychologist who conducted the interviews. Despite the methodology, this might have impacted on their ability to be truly candid about the impact of iatrogenic nerve injury, and again may have introduced some bias.

Contra to the common approach in both natural and social sciences to avoid 'researcher effect' and bias, action research has developed with the express intention of engaging with participants through research feedback in order to influence practice and change outcomes. While we did not design an action research study per se and cannot claim to have undertaken such a project, the data was a useful addition to existing workshop sessions, and enabled patients to reflect and identify with others, and more readily articulate their own feelings and difficulties. This in turn helped them to feel more supported and feel that their voice is heard and acted upon for future practice.

Summary

Through qualitative methods this study has provided an insight into the significant psychological impact of trigeminal nerve injury. Further quantitative research on a larger population would shed further light on the impact of this on the population of affected patients. Further qualitative research could investigate staff perspectives

and experiences, to provide another angle on trigeminal nerve injury, with a view to improving support.

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